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GREAT LAKES HEALTH EFFECTS PROGRAM CASE STUDY: TECHNICAL REPORT #4

EVALUATION OF THE ENVIRONMENTAL HAZARDS PROGRAM

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THE GREAT LAKES HEALTH EFFECTS PROGRAM
A CASE STUDY

by

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The analysis, conclusions and recommendations found in this consultants' report are those of its authors and are not necessarily shared by the Department of National Health and Welfare.

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1. INTRODUCTION

The purpose of this evaluation is to address several questions, on behalf of the Program Evaluation Division of Health Canada, about the performance of the Great Lakes Health Effects Program (GLHEP). These questions, which are presented in Appendix I, pertain to the scope and progress of the Program, the effectiveness with which it communicates with other government bodies and with the general public, and the use the Program makes of the Health Protection Branch's risk assessment and risk management model.

1.1. THE GLHEP

The Great Lakes Health Effects Program[1] is a federal initiative that was created in response to the 1987 amended protocol to the Revised Great Lakes Water Quality Agreement of 1978 between Canada and the United States [International Joint Commission (1988)]. The purpose of the Program, as defined in its mission statement, is

> to protect human health from the effects of exposure to environmental contaminants in the Great Lakes Basin and to promote behavioural change that will foster sustainable health [Haines (1994)],

and three main goals are identified [GLHEP (1993a)]:

1) Determine the nature, magnitude, and extent of effects on human health associated with exposure to contaminants (chemical, microbiological, radiological) from all sources of pollution in the Great Lakes Basin.

2) Develop and implement strategies to reduce or eliminate risks to human health related to pollution in the Great Lakes Basin.

3) Increase communication and consultation amongst agencies and the public and provide timely, useful information to foster understanding and appropriate action on health and environmental issues.

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[1] In the latest *Project Area Reviews*, the GLHEP becomes part of a geographically larger Bioregional Health Effects Program, which also includes the St. Lawrence Health Effects Program and other Bioregional Programs (specifically, the Arctic) [Haines, 1994].

In conducting its work, the Program employs three guiding principles developed through public participation [Haines (1994)]:

- support for the philosophies of prohibition of discharge of substances in toxic amounts (zero discharge) and of the virtual elimination of persistent toxic substances;
- achievement of public participation through developing working partnerships; and
- ensuring effective inter- and intra-agency program co-ordination and co-operation.

This is a large, diffuse and ongoing program, which cannot be expected to have a final goal (as long as there are considered to be public-health hazards from exposure to environmental contaminants in the Great Lakes basin). It involves a considerable range of activities, carried out by five main units within the GLHEP: Public Consultation; Epidemiology; Toxicology; Objectives and Remedial Measures; and Surveillance. In many cases the projects are carried out either by contractors outside government (individuals, universities, public interest groups, etc.) or by members of other governmental departments (federal and provincial).

A distinctive and important element of GLHEP's structure is the existence of an External Advisory Committee. This body, consists of representatives from professional and public sectors. Its role is to provide advice to GLHEP managers and principal investigators, and to act as a direct link between the GLHEP and the various sectors represented by the Committee members. [GLHEP (1992)]

Another distinctive feature is the existence of a consultation unit and the emphasis that is placed on communication with the public. Indeed "Communication and collaboration with the public and other agencies forms a major component of the GLHEP and is addressed under all of the major goals." [Rae and Chu (1993)]

1.2. APPROACH ADOPTED

In conducting this case study, we obtained information from two main sources — structured interviews with federal-government employees associated with the program[2] and a review of pertinent documentation. Our review of documents for this case study

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2 It was not part of our mandate to contact individuals outside the federal government.

was limited to material supplied by the GLHEP and the Program Evaluation Division at the beginning of the study, and documents identified or provided as a result of the interviews. We did not undertake an independent literature search. The documents that formed part of this review are listed in Appendix II

After familiarizing ourselves with the general aspects of the Program through a preliminary perusal of the supplied documentation, a series of interviews was conducted. The initial step involved a short meeting with the contact person identified by the Program Evaluation Division for this case study.[3] During this meeting we briefly outlined the purpose of the case study and asked for names of individuals who would be able to help in answering the evaluation questions (presented in Appendix I). Four people, including the contact person, were identified and face-to-face interviews were carried out. In the course of the interviews, an additional individual was suggested as a person who, as a recipient of information and advice from the GLHEP, would be able to provide us with an opinion on the appropriateness and quality of the information provided by the Program — he was interviewed by telephone. Because the Bureau of Chemical Hazards uses a matrix-project system to achieve its goals,[4] activities in other Divisions than the Great Lakes Health Effects Division within the Bureau also contribute to the GLHEP (e.g., Environmental and Occupational Toxicology Division, Computer Analysis Division). As a consequence, individuals in other groups, who were being interviewed for other components of the Environmental Hazards Program evaluation, also provided information of relevance to the GLHEP case study.

Two team members were used in each face-to-face interview and, prior to each interview, interviewees were sent outlines of the topics we wished to discuss. After each interview, a point-form account of the session was prepared and sent to the interviewee for comment. Comments (if any) from the interviewees were incorporated in the interview accounts and these accounts then formed one of the bases from which we answered the project's evaluation questions.

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3 Dr. Andrew Gilman, Chief, Great Lakes Health Effects Division

4 The matrix-project system is described in the preamble to the *Project Area Reviews 1994-95* [Bureau of Chemical Hazards (1994)].

The topics discussed during the interviews fell into two categories — the program in general and, because it formed a major part of the evaluation questions we had been asked to address, communications — and these are summarised in Table 1-1. Our approach, in each category, was to follow the Health Protection Branch's risk assessment/risk management framework (see Health Canada [1993] for an overview) and we also adopted this structure in the presentation of our findings in Chapter 2. The responses to the interviews are summarised in Appendix III.

1.3 THE ROLE OF SCIENCE

The activities of the GLHEP range from scientific research to communication with the lay public (see for example, *Project Profiles and Progress* [GLHEP (1993b)], but ultimately all are based in science. They therefore include an awareness of what science can and cannot accomplish, and of what might be accomplished by science.

A recurring theme, both in this case study and in the other studies we are conducting as part of the evaluation of the Environmental Hazards Program, is the need to base decisions and actions on sound scientific principles. In the realm of environmental health, this is not an easy ideal to strive for. The scientific uncertainties associated with identifying and quantifying causal linkages between exposure to environmental levels of pollutants and adverse health effects are enormous as, indeed, are the costs and the time that would be needed to carry them out. Given finite resources and limited time frames, therefore, much of the goals of the GLHEP cannot be attained through the strict application of science. The program also has the additional challenge of communicating science-based inferences (together with their uncertainties) to a generally non-science-literate public.

With such a bleak prognosis, one may question whether it is even worth attempting to scientifically attack the questions the Program has been asked to address. We would, however, strongly argue that the attempt is not only worthwhile but necessary. Even when science cannot provide complete answers to the problems posed in the Program's mission statements, it can narrow the possibilities and so enable society's limited resources to be used as effectively as possible in tackling the health threats posed by environmental pollution. Science imposes an analytical rigour which provides a

TABLE 1-1 *Topics Discussed During the Interviews**

THE PROGRAM IN GENERAL

- INTERVIEWEES' RÔLES IN THE PROGRAM
- RISKS IDENTIFIED BY THE PROGRAM AND THE POPULATIONS EXPOSED TO THEM, AND DIFFICULTIES EXPERIENCED IN CARRYING THIS OUT.
- THE MEASURES ADOPTED TO CONTROL THE RISKS, AND DIFFICULTIES EXPERIENCED IN CARRYING THIS OUT.
- THE USE OF RISK ASSESSMENT RESULTS IN THE DEVELOPMENT OF REMEDIAL ACTION PLANS AND OTHER APPROACHES TO REDUCE HUMAN EXPOSURE, AND THE PROBLEMS EXPERIENCED IN CARRYING THIS OUT.
- ARE THERE ANY TRENDS DISCERNIBLE AT THIS EARLY STAGE OF THE PROGRAM?
- WHERE DOES THE PROGRAM GO FROM HERE AND WHAT DOES IT REQUIRE TO GET THERE?

COMMUNICATIONS

- THE PRIMARY "CLIENT" GROUPS AND THE TYPES OF INFORMATION THEY REQUIRE, ITS AVAILABILITY, AND THEIR UNDERSTANDING OF IT.
- THE PURPOSE OF PROVIDING THE INFORMATION AND THE MEDIA USED.
- THE USE OF RISK ASSESSMENT RESULTS IN THE DEVELOPMENT OF COMMUNICATION STRATEGIES AND OTHER APPROACHES TO REDUCE HUMAN EXPOSURE, AND THE PROBLEMS EXPERIENCED IN CARRYING THIS OUT.
- ARE THERE ANY MEASURES OF THE EFFECTIVENESS OF SUCH INFORMATION DISSEMINATION?
- ALTERNATIVE SOURCES OF SUCH INFORMATION AND THE QUALITY OF IT.

* A summary of the responses is presented in Appendix III.

foundation and a framework upon which to base solutions. Properly applied, science makes explicit the gaps in information and requires that, in reaching a given conclusion, one not only identify the gaps but also explain how they are to be bridged. We caution, however, that the science used must be "honest science". There is nothing to be gained by masking decisions made on the basis of non-scientific considerations by invoking "science" as the rationale, and much to be lost. Foremost, perhaps, is the diminished credibility that an otherwise perfectly reasonable decision would have when (as inevitably it must be) the masking is spotted. If something cannot reasonably be answered by scientific explanation then one should say so and acknowledge that other means have to be used to develop the conclusion.

It was observed, during our interview discussions, that if Health Canada does not do the "science", other entities (who may use less rigorous approaches) will. And, without a solid commitment to science, there is a danger that the program could become hostage to the process known as "policy entrepreneurship" — a term used by political scientists to describe the activities of various governmental and business decision-makers, and interest-group leaders, who cultivate "public opinion" in order to further a particular, self-interested course of action

2. FINDINGS

Our findings in this evaluation are presented under two broad headings: risk assessment and risk management. In both these activities, communication, with the public and with other agencies, forms a major, common thread. Moreover, communication is the major component of the evaluation questions we have been asked to address.

2.1 RISK ASSESSMENT

The risk-assessment model as described in the document, *Health Risk Determination: The Challenge of Health Protection*, formally consists of four stages: hazard identification, risk estimation, the development of possible options to manage the risk, and the analysis of those options, in preparation for the subsequent, risk management, phase. [Health Canada (1993)] Although there are formal, even numerical, procedures that can be applied at almost every stage of the risk assessment/risk management process, the model as described in *Health Risk Determination: The Challenge of Health Protection*, "is not intended as a rigid structure in which each of the steps is taken in sequence. Rather, the model provides a general framework within which flexibility can be introduced on a case-by-case basis." [Krewski *et al.* (1993)] This flexibility is necessary, not only to accommodate the complexities and limitations of data that are almost certain to arise when one deals with public health, but also to acknowledge scientific uncertainty.

In many circumstances, quantitative risk evaluation is an activity that is either impossible to perform with scientific rigour or that requires great effort and resources if it is to produce meaningful results. Rather, risk-assessment activities provide a framework on which less formal decision-making processes may be implemented — e.g., the "zero discharge" philosophy that underpins the Program's actions on persistent toxic substances.

To some extent, the same arguments can be applied to attempts to estimate the number of persons potentially exposed to health risks from environmental contaminants.

Although some groups at special risk can be (and have been) identified,[5] estimating the numbers of individuals involved may often be seen as a time-consuming, expensive and academic exercise that adds little to the Program's productivity or sense of direction. Indeed, for many environmental contaminants, the group potentially exposed is the whole population of the Great Lakes basin.

As a result, the risk assessment practices of the GLHEP generally deviate from the canonical version of the HPB risk assessment and risk management model. Typical GLHEP practice is to emphasise hazard identification and, where possible, then move more or less directly to risk management. This choice bypasses quantitative or semi-quantitative risk assessment and the development and evaluation of a range of risk-management options. And, given the breadth of the undertaking, this approach may well be the most efficacious.

This is not to say that some form of risk estimation plays no role whatsoever in the activities of the GLHEP. In specific cases, such as the on going case-control cancer study and the respiratory hospitalization-rates study [projects #221 and #222, GLHEP (1993b)] summarised in Table 2-1, formal risk estimates are being made.[6] More commonly, less formal methods of risk assessment are made, including estimates of the proportions of people exposed in groups at risk, and estimates of exposure to pollutants known to be hazardous.

To some extent the business of risk assessment (and, indeed, hazard identification) is taken out of the hands of the GLHEP by the fact that the International Joint Commission has identified regions within the Great Lakes Basin as Areas of Concern. Thus, it could be argued, these areas become by definition matters of priority,

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5 For example: owners and employees of sport-fishing operations, and immigrant groups that traditionally have a high proportion of fish in their diet.

6 The principal investigators in both these studies, however, are from outside the Great Lakes Health Effects Division. The studies involve collaboration with other groups within the federal government (e.g., LCDC, Environment Canada) and outside agencies (e.g., Ontario Cancer Treatment and Research Foundation, Harvard School of Public Health).

and GLHEP plays a role as a health-effects advisor in the development of Remedial Action Plans (RAPs).[7]

2.1.1 Communications

In the area of risk assessment, GLHEP communicates with both the public and with other agencies. In each case, the Program acts as both a source and a two-way channel of information related to hazard identification and risk assessment.

As we noted above, communication with the public is an explicit aim of GLHEP, as part of all its projects.

The GLHEP has made considerable efforts to ensure that information and advice reach its "target" groups effectively. Some of these efforts, including participating in Town Hall meetings convened by local authorities and the holding of workshops with various interest groups, enable public perceptions of risks and needs to be addressed directly. In this sense they play a part in risk assessment by raising concerns about topics that can be addressed by the program. In a similar way, some of the direction of GLHEP's risk assessment activities also comes from the program's External Advisory Committee.

These routes of communication also serve to provide information on the progress of investigations, and on the findings from a completed study. Often such information is provided to public bodies, notably to communities who participated in research studies that produced the data on which the risk assessment is based. Such communication can be regarded as fulfilling a simple right to know, as educating the public about risks, encouraging the public to indicate their own perceptions of risks and needs, and in many cases as acting as risk management by encouraging changes in behaviour so as to reduce

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7 Under the international Great Lakes Water Quality Agreement both Canada and the United States are developing pollution clean-up plans. Most of these are Remedial Action Plans (RAPs) that deal with highly polluted local Areas of Concern (AOCs) These plans require extensive participation from all groups that have a stake in protecting the Great Lakes — public officials (federal, provincial, municipal), representatives of industry and universities, citizen groups, and concerned individuals. [Boyer (1991)]

exposure or risk. Instances that clearly fall into the latter category are discussed under the heading of risk management below.

A major component of the GLHEP's risk assessment activity is providing up-to-date information on matters relating to human health and environmental contaminants to other agencies. This information may be the results of the GLHEP's own projects, or published data (for example on toxicity) identified by GLHEP staff. Some of this information is provided to other federal departments, such as Environment Canada and agencies in the United States, such as the Agency for Toxic Substances and Disease Registry (ATSDR) [DeRosa (1994)]. It appears that the GLHEP is the most effective, and in many areas, perhaps the primary Canadian source of health-related information and advice on matters relating to the Great Lakes basin. The quality of such information was generally regarded as high by the recipients,[8] with the occasional reservation that the presentation is somewhat too technical for its intended audience — a common criticism of such information from all sources.

2.1.2 Research

One of the first responses to a perceived potential hazard is to investigate it scientifically, and scientific research has formed a large part of the GLHEP's efforts that can be classified as risk assessment. The focus of these research projects has been to investigate the relationship between contaminant levels in the environment or human tissues and possible health effects. These studies range from attempts to elucidate specific mechanisms of toxicity to attempts to establish correlations between tissue levels of groups of compounds and measures of human well-being. The scope of the scientific research carried out by the GLHEP is illustrated by the examples presented in Table 2-1. In the coming year, the fraction of the GLHEP budget devoted to research will decrease from about 60 percent of the total to about 12 percent, with a corresponding increased emphasis on education and surveillance and corrective action [Haines (1994)].

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8 An impression gained from comments by the Program staff interviewed, and corroborated by the one representative of Environment Canada we interviewed and by a written memorandum from DeRosa (1994).

TABLE 2-1 *Examples of Research Projects Carried Out by the GLHEP**

GLHEP UNIT	PROJECT DESCRIPTION	PROJECT NO.
Epidemiology	investigation, in a case-control study, of possible causal relations between exposure to Great Lakes pollutants and cancers of the stomach, colon, rectum and bladder taking into confounding factors such as socioeconomic status, medical history, dietary pattern, smoking and ethnic origin	221
Epidemiology	examination of the effects of ambient air pollution on the respiratory health of individuals living in the Great Lakes Basin, by compiling rates for hospital admissions for respiratory illnesses for each census subdivision in Ontario, and attempting to relate these rates to corresponding levels of ambient air pollutants	222
Toxicology	studies using monkeys on the effects of neurotoxicity caused by chronic exposure to mercury and lead for different periods of time (in the case of mercury, including exposure *in utero*).	37
Toxicology	investigation of the effect of chronic lead exposure on fertility in the cynomolgus monkey, the aim being to extend knowledge of the effects of lead on reproductive physiology and so provide information needed to assess the human risk from lead intoxication	310
Toxicology	investigation of the toxicity and physiological properties of specific PCBs, with the aim of providing data on the specific PCBs found in food and human tissues, and for which toxicity data are lacking	15
Objectives and Remedial Measures	radiological impact assessment of Port Hope, to consider the cumulative effects on the present population of exposure to radionucleides from all sources and pathways associated with the uranium processing industry in Port Hope	236
Surveillance	investigation of the largely unknown area of the effects of priority Great Lakes contaminants on human fertility and male reproductive endpoints in general, making use of human follicular fluid from *in vitro* fertilisation programs in six Canadian cities; together with sperm samples, these samples will be analysed for contaminants and for sperm morphology and functional characteristics and related to the efficiency of fertilisation; the combined data will be used to investigate the possible effect of trace levels of contaminants on various reproductive outcomes	30
Surveillance	use of human placentas (normally discarded as waste) in a pilot program as tissues to monitor exposure to organochlorine contaminants; this project would provide data on a group for which levels of contamination are not known at present; a similar project makes use of human fatty tissue, to provide a tissue bank; both projects are intended to assess human exposure to toxic chemicals and provide evidence as to whether levels of toxic chemicals are increasing or decreasing in the Great Lakes region.	203, 204

* Source: GLHEP[1993b]

Much of the Program's research, particularly that undertaken by the toxicology group, lies within the preliminary but crucial stages of risk assessment — the work of laying a foundation of basic understanding upon which more precise assessment of human risk can be based later. Such work cannot become part of a quantitative risk assessment until its results have been assimilated and their implications for public health determined. In many cases research projects must be carried on in parallel with preliminary attempts at risk assessment and often with risk-management programs — both of which may have to operate on the basis of the best current information, rather than awaiting a final scientific analysis.

While it is relatively easy to assess the productivity of a research program in such terms as numbers of projects completed, reports written and papers published, assessing the quality of the research is much more difficult. Indeed, without carrying out a review of the plan, methodology and results of each project, it is virtually impossible. The wider question, relevant to this evaluation, of how effectively a given research project contributes to the GLHEP's goals, presents a still more difficult problem, and one whose solution does not seem to have been developed.

2.2 RISK MANAGEMENT

Specific regulatory controls aimed at protecting the public from adverse effects of environmental pollutants are generally lacking at the Federal level.[9] True, Health Canada has the *Food and Drugs Act* which provides the power to prevent excessive human exposure from pollutants in food, but the regulatory powers it grants Health Canada are rarely used to control chronic exposure to environmental pollutants. The options available to the Great Lakes Health Effects Program to control pollution or otherwise work to improve human health are therefore limited.

Communication, in a broad sense, remains the only practical risk-management option available to the Program. Within this broad category there is considerable variety. One can imagine, for example, occasions arising where the Program, having identified a particular hazard, could approach another government agency that does have legislative

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9 Environmental controls are, by and large, a provincial responsibility.

powers relevant to the problem in question with the aim of having the appropriate regulations developed and enforced. A less direct approach, but one with possibly broader application, involves the setting of guidelines for pollutant levels in food, water, or air.[10] Even though such guidelines have no legislative force, they may be effective in reducing human exposure — one cannot imagine, for example, that any municipality in its right mind would intentionally provide water above limits specified in the *Guidelines for Canadian Drinking Water Quality*. But the bulk of the communications efforts consists of advice or consultation with the aim of increasing awareness and altering public behaviour.

A difficulty faced by any governmental body dealing with the public is, as was pointed out by one of our interviewees, the fact that government statements are generally distrusted. On the other hand, there is a public need for information relating to human health, and if governmental agencies do not fulfill that need, it will almost certainly be filled by other groups that have their own agendas. A government body that tries to use direct communication as a means of improving public health therefore is faced with the need to overcome public distrust so as to ensure that public receives the most trustworthy information and advice available (and with some indication of the attendant uncertainties).

The GLHEP has made considerable efforts to communicate with the general public, both directly and indirectly. These efforts have been directed at professional or technical groups that interact with the general public, at special interest groups and at the public as whole.

Professional or technical groups, (the most important being health professionals and educators) that are in contact with a large fraction of the population and generally trusted by it, can act as intermediaries in transmitting health-related information and advice to the public. Among these groups, Ontario Medical Officers of Health have very wide powers and responsibilities for dealing with all matters of public health. They therefore form a potentially very powerful instrument for the Program's efforts to

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10 Here the "matrix project system" adopted by the Environmental Health Directorate provides an avenue for the GLHEP to influence the setting of such guidelines.

improve environmental health. Through presentations to Canadian Public Health Inspectors and activities such as workshops cosponsored with the Ontario Public Health Association [Ontario Public Health Association (1992)], the GLHEP has established links with local health units and developed plans for further action. Physicians and other health professionals have a closer contact with the public, and they too have been a focus of GLHEP communications, through presentations and articles providing advice on environmental health published in *Canadian Family Physician Journal* [Haines (1994)]. A pilot study to investigate the possibility of setting up an environmental health information service for health professionals was recently completed [Austin (1994)].

Educators form the group that has perhaps the greatest potential ability to influence public opinion and behaviour in the long term. The GLHEP's efforts to inform them about matters pertaining to environmental health have included workshop presentations and fact sheets and video presentations for teachers [GLHEP (undated a)].

Contacts with the public either directly or through special interest groups have involved workshops and presentations to groups such as seniors [Rae and Chu (1993)], Canadian Organic Growers and women's groups [Haines (1994)]; and the production of fact sheets for the general public [GLHEP (undated a)].

Attempts have been made to identify and reach groups perceived to be at risk. Examples would be immigrant groups that traditionally have high a proportion of fish in their diet, and traditional ways of preparing fish that may not be the best for controlling the intake of pollutants from contaminated fish. A GLHEP fact sheet exists to provide advice on these matters [GLHEP (undated b)], but whether it would be effective in communicating with immigrant groups is open to question. The Program, in fact, investigated ways of improving such communication in a recent study [Clark (1993b)].

A major area in which the Program regularly provides health-related advice is in the development of Remedial Action Plans (RAPs) for areas of concern (AOCs). The Program's advice to RAP committees is an example of its communication with a combination of technical and special interest groups. In addition to providing information and advice to the RAP committees on health-related aspects of RAPs, GLHEP staff keep Provincial epidemiologists and the Medical Officer of Health in the

AOC informed of new health-related data that are developed for the RAP. And on occasion, advice from GLHEP prompts new investigations. [GLHEP (undated c)]

Judged simply by the numbers of presentations given, reports published, the effort expended in risk management through communication is successful. Such measures are in fact, at present, almost the only estimates of the effectiveness of these programs. In future it may be expected that the GLHEP will devote more effort to trying to assess how well these public communications are understood and what effects they have on public behaviour as it influences environmental health.

3. CONCLUSIONS AND RECOMMENDATIONS

The GLHEP's approach to public health is manifestly proactive. Given this approach and the limited number of personnel available to the GLHEP together with the need for projects to produce results within a reasonable time, formal, quantitative risk evaluation cannot be expected to be given a high priority among the Program's activities. Instead its efforts are focused on identifying hazards and using communication as a means of risk management.

Indeed, a major role of the GLHEP that falls within the scope of this evaluation is that of "information broker". The Program supplies health-related information (from its own research and from the literature) and advice to a variety of bodies both within government and in the private sector. The content, intellectual level and media of presentation of the advice and information depend on the needs of the "target" group. The purpose of such advice and information is also varied, and its effectiveness can in most cases be judged only indirectly, but what evidence we have gathered indicates that the quality is generally high and no other body would be as effective in providing it.

In terms of its own objectives, the GLHEP has performed well in conducting Goal 1), and very well (and imaginatively) in accomplishing Goal 3), but there is scant evidence (among the documents we were provided with)[11] that the Program has formally developed "strategies" aimed at reducing exposure and adverse health effects, as required under Goal 2).

We cannot help but express an admiration for the approach taken by the GLHEP. What is being attempted is ambitious and employs considerable innovation (for the Environmental Health Directorate, at least) in reaching out and encouraging the "public" (be they special interest groups, small enterprises, public health professionals, and so on) to grapple with the meaning of and response to environmental contaminants and human health. In the long run, we would suspect, such public involvement can only lead to a

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[11] We hasten to add, however, that because the evaluation questions being addressed in this report (Appendix I) did not specifically address strategies to reduce or eliminate exposure, we made no attempt to investigate them.

reduction in exposure and so (if the pollutants are chosen wisely) to a possible improvement in public health.

> *This being so, we recommend that the Program be encouraged to continue and develop its efforts in combining scientific interpretation with public understanding and action.*

From the point of view of an evaluator, however, it would be desirable that this continued effort be accompanied by a more formal expression of the means by which the Program's activities could lead to a reduction in exposure to environmental pollutants.

If we have a quibble, it would be with the variability in quality of some of the Program's publications. The trivial and imprecise content of a couple of GLHEP publications dealing with communication [MacKay (1991), Clark (1993a)], for example, contrast starkly with the thoughtfulness, clarity and accuracy of the series of articles published in last year's *Canadian Family Physician Journal* [Mortimer (1993)], or the informative, useful and pertinent handbooks on *Investigating Human Exposure to Contaminants in the Environment* soon to be published by the Program [GLHEP (undated d)].

> *We recommend that the Program take efforts to ensure the highest standards in their publications.*

To do otherwise, would unjustly undermine the credibility of the Program and detract from its effectiveness.

As we pointed out in the introductory sections of this report, the Program is large and diffuse with no final goal. These characteristics make it very difficult to judge to what extent the Program's activities are fulfilling its mission statement.[12]

> *We would therefore encourage the Program to pursue the development of indicators of the Program's effectiveness.*

We have to admit, however, that we do not have concrete suggestions as to the form that such indicators might take. In many cases, physically measurable parameters (changes in

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12 "To protect human health from the effects of exposure to environmental contaminants in the Great Lakes Basin.

environmental levels and the like) may not, at least in the short to medium term, be the most appropriate indices of effectiveness. Rather, it is likely that some measures of human behaviour (changing eating habits among sport-fish eaters, for example) and effectiveness of communications would prove most useful.

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APPENDIX I: SCOPE OF THE GLHEP CASE STUDY

The purpose of the study is to evaluate:

> The investigation of the health effects associated with exposure to environmental contaminants in the Great Lakes Basin and the provision of information, advice, and consultation to foster action to reduce or eliminate the risks to human health from these contaminants.
>
> To the extent possible, the case study should include an estimation of the number of persons potentially exposed each year to health risks from the environmental contaminants investigated, the level of health risk, and the severity of that risk.

and to answer the following questions on "the actions taken and advice given by the Environmental Health Directorate" with regards to the GLHEP:

(1) Q7a. EHD provides information and advice to governments, departments, agencies, and others to help them manage the health risks from environmental sources:

   (a) Do client decision makers get timely and needed information from EHD on health risks from environmental sources?

   (b) Does EHD provide the information in a useful format?

   (c) If EHD didn't provide this information and advice, where would these clients turn for information and advice? What would be the consequences if this were to happen?

(2) Q6. How effectively does the program communicate with specific interest groups and with the public about actual public exposure to radiation and chemical hazards, and known health risks from such exposure?

(3) Q1. Do these case studies suggest a need for specific changes or improvements to the way the Environmental Health Directorate uses the HPB Risk Assessment/Risk Management framework in planning and conducting its operations? Are there factors that must be addressed which fall outside of the HPB framework?

It was, however, outside the mandate of this study to make contact with individuals and organizations that were outside the federal government. (Such contacts are to form another part of the program evaluation.) For the purposes of this project, the "client" referred to above constitutes other federal government departments (notably, Environment Canada) and the public at large.

APPENDIX II: BIBLIOGRAPHY PERTINENT TO THE GLHEP CASE STUDY

The following is a list of documents that we were provided with during the course of the case study.

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APPENDIX III: SUMMARY OF INTERVIEW TOPICS AND THE RESPONSES[13]

Interviewees: Four representatives from Health Canada, and one representative[14] from Environment Canada.

THE PROGRAM IN GENERAL

Interviewees' rôles in the program:

- varied.

Risks identified by the program and the populations exposed to them, and difficulties experienced in carrying this out:

- Risks:

  Reproductive; cancer; developmental (foetal and from impaired care of newborns); immune system; respiratory health risks.

  The population exposed is the general population — almost unquantifiable.

- Specific populations at risk:

  Those with compromised respiratory health (ozone excursion produces increase in hospital admissions within 24 h).

  Those eating large amounts of contaminated fish (and other wildlife).

  E.g.: pregnant women & developing foetuses; native peoples; charter-boat operators; some (south-east Asian) immigrants.

  The elderly (lack of regenerative power; sometimes a compromised life-style).

  Those in ill-health (other than respiratory problems), especially from liver or kidney disease (susceptible to environmental cadmium or uranium).

  Children (consume relatively large amounts of food per body mass, and their tissues are still developing). Breastfeeding newborns are a subset (but risk lower now that lead is reduced in the environment).

  Foetus (most susceptible to metals and toxic organics).

  Those who are respiratorily compromised.

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13 By and large, each bullet corresponds to a response from an interviewee and thus there will be instances of repetition.

14 Telephone interview

- Risks are not quantified *per se* as the Program doesn't believe in playing with numbers.
- When a possible hazard is identified, the Program will 1) do animal experiments to determine toxicity (within HPB or contract), 2) look at exposures (levels, types of) for human health, 3) look at health effects studies .
- The Program uses the services of Environmental and Occupational Toxicology Division for toxicology testing, LCDC for epidemiology, etc.
- The Program obtained background information from provincial cancer agencies and developed atlases for cancer and birth defects to identify "hot spots".
- The Program tries to not just look at narrow problems but uses more general approach, combining information from many sources to get a more accurate picture of "risks".
- The Program looks at information based on global data & literature.
- Statistics Canada and provincial agencies (e.g. hospitals) are sources of data.
- IJC (International Joint Commission) would like to look at each lake as a whole in terms of ecosystems and human health — not just Areas of Concern (AOCs) individually.
- The Program would like to establish standardized indicators for surveillance of contamination trends, within IJC/RAP lake-wide plans.

The measures adopted to control the risks, and difficulties experienced in carrying this out

MACRO:

- Development of guidelines for exposure media .
- Advice for public.
- Recommendations to MDs or public regarding, for example, cooking & serving fish, and breast feeding.
- Communication of information through various routes.
- Contaminant control options (CEPA-like activity): for example, substances of interest to GLHEP can be handled under CEPA; Canada's role in international concerns would be through CEPA.

MICRO:

- Guidelines (e.g. for PAHs in sediment; criteria for waste-dump cleanups).

- Advice to MDs on blood-contaminant levels & population ranges to give perspective.
- Communication strategies — aimed at populations most at risk.
- Tiered documents, ranging from grade-13 level to tear-out sheets and pamphlets.
- Teacher-aid kits: for example, video & hard copy, finger puppets.
- Packages for RAP sites — site-specific, prepared using data from LCDC and Statistics Canada.
- "Townhall meetings" sponsored by community groups.
- Information meetings convened by GLHEP to provide information to a professional group, e.g. Health Professionals (ca. 40 presentations per year).
- Messages targeted to specific groups at risk (e.g. pregnant women, anglers, seniors with respiratory problems etc.).

CONTROL OPTIONS:

- Working with Ontario MoE for phase-out of persistent toxics. (Rate of decline of contaminants is now levelling off; perhaps limited by long-range transport.)
- Goal of zero-discharge for persistent toxics (e.g. closed loops in industrial plants); "zero" defined by detectability under chosen measurement technique.
- The Program is pushing for international protocol on persistent toxins.
- The Program is looking towards further domestic controls on dioxins.

PROBLEMS EXPERIENCED:

- The lower the contaminant levels, the harder it is to identify the risks.
- Effects generally subtle; new tools needed to measure them.
- No experimental & control groups.
- Most RAP members are "wild life" oriented and Program finds it important to push to get human health issues included in the RAP approaches.
- The Program is aware that working with community groups may generate unrealistic expectations, leading to reluctance to cooperate when such expectations are not speedily dealt with.[15]

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15 If we may be permitted a comment: In many, if not most instances, remedies take years to develop and even longer to see tangible results.

- The Program experiences difficulties in getting and working with case data (e.g. sperm counts).
- The slowness at which scientific information becomes credible enough to be used in governmental policies (when the latter may be controversial or costly) leads to a slow regulatory process. Therefore hard to develop & put in place formal control structures (it took ca. 5 years for furan/dioxin regulations, for example).
- The Program will get data from animal experiments, but animals are not humans and may respond differently.
- "Microbial risks" (protozoa, viruses, fungi) to public do not appear to be being considered as much as "chemical risks", in the Great Lakes program and that these may be just as hazardous.
- Immigrant populations at risk can be more difficult to address, given cultural and language differences (the Program is currently working on communicating with these communities and their leaders).
- Industries and unions have been hesitant to interact with GLHEP expressing concerns about losing jobs etc. Progress has been made towards a "sharing" of information between GLHEP and industry scientists, including interaction with the Council of Great Lakes Industries (linked with chemical, auto, and pulp and paper industries).
- Request for speakers works quite well and more Program staff are getting involved.
- The Program experiences difficulties in producing information in a form people want, fast enough.
- Initial response to a question is usually easy, but response to follow-up questions gets more difficult.
- Government approval to publish information is slow — Birth Defect & Cancer Atlases stalled for ca. 2 years; now going ahead, but with 1988 data.

The use of risk assessment results in the development of Remedial Action Plans and other approaches to reduce human exposure, and the problems experienced in carrying this out

- It is usually difficult to assess risks (for RAPs) and this is not the main role at present.
- In general, risk assessment is not practical, but the Program does educate RAP committees by showing them the complexities of answering certain, seemingly simple, questions (e.g., "Is it safe to swim here?").
- Most input from Program has occurred at Level 1 (problem definition) of the RAP process.
- Level 1 concerns are used to try to plan logical ways to address problems effectively.

- Most RAPs are now at Stage 2 — determining what actions should be (with public advisory committees' input) and obtaining funding to follow actions through.

Are there any trends discernible at this early stage of the program?

- Epidemiologic investigations in the Great Lakes area are showing increased incidence of prostate cancer, breast cancer, lymphomas, infertility and decreased incidence of stomach cancer. How much, if any, of these changes is linked to pollution cannot be estimated.

- Decreases in contamination levels in Great Lakes (now levelling off) and decreased levels of lead (due to unleaded gasoline) are being observed. Poor economic conditions have shut down factories and industries, therefore some reductions in contamination are not due to changes in regulation or improved education.

- There is a shift away from concerns about mercury and lead. Cancer, low birth weight and infertility are current concerns.

Where does the program go from here and what does it require to get there?

- The Program faces another 6 years of "limping along" with inadequate resources.

- The Program would like to have resources for more thorough survey(s).

- The Program will be carrying out effectiveness analysis and provide regular publication of how program is meeting targets.

- The Program will be developing indicators of exposure and effect (mainly exposure) through public consultation.

- The Program will be putting much more emphasis on getting information out, including risk-management packages.

- Sustained commitment and sustained funding (but perhaps not to support the current levels of health research) is needed. (Spent $60,000–70,000 last year on salaries to rationalise fluctuating budgets.)[16]

  Research will fall from 70% of funding to 45–50%.

- The success of the Program depends on quality people with enthusiasm, sense of mission, and willingness to take risks.

- The Program will continue to pursue good partnerships with other groups — e.g. Universities, provinces — as GLHEP doesn't have all the expertise or the dollars.

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16 Our understanding was that this expense occurred as a result of the need to reschedule programs and cancel or rewrite contracts.

COMMUNICATIONS:

The primary "client" groups and the types of information they require, its availability, and their understanding of it

SPECIFIC:

- Educators want reference materials, visuals, handouts for classes, course modules.
- External Advisory Committee meets 4 times per year; reviews GLHEP budget and project proposals to set priorities in consultation with GLHEP.

  External Advisory Committee (consists of representatives from the public, groups like Greenpeace, industry, provincial health etc.) set priorities of problems they would like addressed. Final decision within Health Canada, but they probably wouldn't overrule the committee. Doesn't feel this is a problem. Only criticism is that many academics and the public don't understand the difficulties in working within government system (in terms of political interference causing delays, lack of funding etc.).
- Women's group didn't want packages, but access to science (from & about women) in presentations and discussions.
- South-east Asian Groups wanted no questionnaires or surveys (distrust of government) but would talk to care workers. Wanted pictures of fish they should eat less of and information on preparing fish (but may have ignored it); didn't want reports.
- Physicians: some not willing to be convinced of the importance of environmental health effects; some wanted stronger reports, social statements; some wanted to learn more, but didn't have time (and wanted a manual).

  GLHEP is working with task force of health professionals to include health and contamination issues in training courses.
- The Program acts in an advisory role to the St. Lawrence Health Effects program.
- Health Canada has a major role in the health component of the SOLEC conference. GLHEP personnel are part of the U.S./Canada State of the Lake Ecosystem Conference (SOLEC) committee and will be reviewing and providing information regularly.

GENERAL:

- The GLHEP works with groups at risk — e.g. sports fishermen, immigrants, people who drink water, general public etc. — in outreach programs.

- GLHEP client groups are: RAP and PAC[17] committee members, AOC communities, Provincial epidemiologists, Medical Officers of Health, EAGLE (and other native groups), DFO, External Affairs, DOT, DOE, Great Lakes Research Consortium, IJC, CWS, U.S. EPA, Agency for Toxic Substances and Disease Registry (ATSDR).

- GLHEP are the primary source of any information needed on human health impacts, e.g., recent studies in general; information on cancer and respiratory problems related to environmental stressors, especially contaminants.

- Education of people and "putting problems in perspective" an important part of the GLHEP's job .

- It has been the Program's experience that people making inquiries are not stupid and the Program finds that their comprehension of answers/problems/limitations is good.

- The Program assumes an active role of identifying problems that other groups should be addressing (e.g. regulation of bilge water dumping).

- The Program is usually engaged in answering requests from clients for comments on scientific reports, information/data about geology, landfills, air quality, contamination levels etc. for different regions.

  Client groups include health professionals, industry, women's groups, media, teachers, daycare workers, land owners etc.

- The GLHEP has consulted with representatives from all these groups to determine what they wanted and needed (and this, in turn, helps to better define the Program).

- The GLHEP produces information at "different levels" for all these groups and sends appropriate package to each — e.g. Handbook for Health Professionals (in progress), articles in local community newspapers.

The purpose of providing the information and the media used

- Canadians have asked for it because they are interested in health and the environment.

- As a society, we have to know where health risks from the environment are. Providing information to other regulators helps form policy.

- Information provided to the media and the public helps to counteract negative reporting and informs the public on the basis of what is known, not what is myth. (There is a major distrust of government.) But it may be hard to get the information

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17 Each RAP has a Public Advisory Committee (PAC) whose function is to ensure public involvement in the RAP itself [*RAPs and Human Health in Canada's Areas of Concern.* (fact sheet). Ottawa, Ont.: Great Lakes Health Effects Program, Department of National Health and Welfare (undated)].

(e.g. Food Directorate don't want media coverage on pollutant levels in breast milk).[18]

The use of risk assessment results in the development of communication strategies and other approaches to reduce human exposure, and the problems experienced in carrying this out

- Information is supplied by GLHEP as needed (several time per year). Examples would be suggested RAP projects that involve human health studies; these would automatically go to GLHEP for review.
- GLHEP can only suggest changes in behaviour and/or inform tested individuals where they rank on a scale of contamination levels from other tested individuals (the Program believes you can't predict the outcome on an individual basis).
- The goal is eventually to have teachers, mayors, doctors etc. able to answer questions pertaining to health issues in their area (based on accurate, current information).
- Initial response to a question is usually easy, but response to follow-up questions gets more difficult.

Are there any measures of the effectiveness of such information dissemination?

- The Program has not carried out much investigation of effectiveness yet, except a little before-and-after questionnaire work.
- Comment sheets are provided on back page of draft handbooks — several responses have been received and are on file — and a workshop is planned to get feedback on draft handbooks.
- The Program might be able to measure reduction in respiratory admissions to hospitals (but would have to consider, e.g., whether cases were treated as outpatients).
- Measures of activity (e.g. number of meetings and presentations) provide one indication of Program effectiveness.
- The Program receives direct feedback from RAP committee members.
- The External Advisory Committee (members from non-governmental organizations) provided the GLHEP with feedback at beginning of Program.

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18 We did not explore this comment during the interview, but would like to point out that extensive data concerning contaminant levels in Canadian breast milk are provided in the report, *Toxic Chemicals in the Great Lakes and Associated Effects. Volume I — Contaminant Levels and Trends*, Tables 3.3a to 3.3s. [Supply and Services Canada, Catalogue No. En 37-95/1990-1E (March 1991)].

- The Program gets direct feedback from meetings with community groups, public displays, and so on.
- Accountability sessions have been held with different sectors to determine where improvements could occur (for both parties).
- Articles appearing in community papers list the Program's phone number for information (can keep track of calls received).
- Questionnaires are handed out at meetings (asking for suggestions, usefulness of information etc.).
- The Program could monitor the number of GLHEP videos were requested by schools and other organizations and/or the number of times a video is aired on TV (becomes difficult to do).
- The GLHEP is very helpful and information is generally provided quickly, and in useful format (although the language may be too technical for managers at the conference, and need to be rewritten — a common feature of such material from all sources).

Alternative sources of such information and the quality of it

- There is none outside EHD.
- The Program's rôle is to teach people where to get reliable information fro themselves and not to exclusively rely on information from GLHEP .
- The Program provide other sources of information as bibliographic "GLHEP Documents" — information from IJC, AES, The Great Lakes Program etc.
- McMaster University is setting up an information service for M.D.'s and nurses with information from GLHEP and others.
- Other information is available from Institute for Environment and Health.
- The public can usually obtain information from federal, provincial and/or Municipal government .
- One client sometimes uses the U.S. ATSDR (and in absence of GLHEP, would use them as a source more often), but Health Canada would be and is the first choice.